

HIV/AIDS Surveillance

FACT SHEET

STATE HIV/AIDS SURVEILLANCE PROGRAMS

HIV/AIDS surveillance activities monitor the HIV/AIDS epidemic in the U.S. and provide data that are critical to targeting the delivery of HIV prevention, care and treatment. State health departments are uniquely able to conduct these activities because of the expertise, statutory authority, and confidentiality protection of existing public health disease surveillance and reporting systems. HIV is the virus that causes AIDS and therefore HIV surveillance reflects the current epidemic, while AIDS case data provides a picture of the older epidemic. With the advent of anti-retroviral therapy people are not progressing to an AIDS diagnosis at a rate as was previously predicted. Many people feel that it is important to capture HIV cases as it alerts public health departments and providers to HIV outbreaks and emerging trends in communities.

There are four main types of HIV/AIDS surveillance funded by the Centers for Disease Control and Prevention (CDC). They are discussed in detail below.

CORE SURVEILLANCE

Core surveillance is the primary source of population-based data on persons living with HIV/AIDS in the United States. AIDS case surveillance is conducted in every U.S. state and territory, as well as the cities of Chicago, Houston, Los Angeles, New York, Philadelphia, and San Francisco. AIDS cases are reported by name by all states. Several states, territories and highly-impacted cities have only recently implemented this process for collecting HIV data and it is not uniform across the

jurisdictions. Forty-two jurisdictions currently conduct HIV surveillance using a name-based system. The remaining jurisdictions use a code, name-to-code, or a name-optional system to collect HIV data. The following core surveillance activities are conducted by states and territories:

- Monitoring the number of yearly cases of newly diagnosed HIV infections, the prevalence of persons living with HIV/AIDS infection and HIV/AIDS-related morbidity and mortality.
- Monitoring perinatal exposure to HIV and HIV/AIDS infection in infants.
- Using collected data as a guide for allocation for federal and state resources for HIV/AIDS treatment, care and other services.
- Collaborating with health care providers, laboratories, community groups and organizations to identify changes in trends of HIV transmission.

INCIDENCE SURVEILLANCE

HIV incidence surveillance attempts to provide reliable and scientifically valid estimates of the number of **newly acquired** HIV infections at the local, state, territorial and national level. Eligible jurisdictions must possess HIV reporting systems, and they must have a sufficient number of reports on new, annual HIV diagnoses. Twenty-seven states, six cities, the District of Columbia and Puerto Rico were eligible to apply for CDC funding in the last funding cycle to conduct HIV incidence surveillance. HIV incidence surveillance collects samples of specific HIV specimens and tracks the different HIV strains seen in the jurisdiction. Jurisdictions that

conduct HIV incidence surveillance conduct the following activities:

- Collecting and testing diagnostic blood specimens from all newly reported HIV infections.
- Calculating population-based estimates of HIV incidence using collected HIV testing information.
- Monitoring and tracking HIV strains for resistance to antiretroviral drugs.

BEHAVIORAL SURVEILLANCE

Examining behaviors that put people at risk for HIV infection is a key element of a comprehensive integrated surveillance system. Behavioral surveillance focuses on those groups who are at highest risk for infection, mainly Men Who Have Sex with Men (MSM) and Injection Drug Users (IDU). Behavioral incidence grants are awarded to 26 Metropolitan Statistical Areas (MSAs) with the highest number of people living with HIV/AIDS at the end of 2000.¹ Jurisdictions who receive behavioral surveillance funds conduct the following activities:

- Developing an ongoing surveillance system to ascertain the prevalence of HIV risk behaviors among groups at high risk for HIV infection for use in developing national prevention services and programs.
- Engaging community-based organizations (CBOs) in research and questionnaire development.
- Collaborating with HIV/AIDS prevention programs to assess exposure to and use of HIV prevention programs.
- Disseminating study data for use in state/local prevention and in treatment services planning and evaluation.

ENHANCED PERINATAL SURVEILLANCE

Enhanced perinatal surveillance targets and tracks the progress of the reduction of perinatal HIV transmission. Enhanced perinatal funds go to state and local health departments that are in high-morbidity areas (60 or more

HIV-positive women giving birth) that have implemented HIV surveillance for adults and children. Ten states are currently funded. Jurisdictions that receive perinatal surveillance funds conduct the following activities:

- Conducting medical record review and follow-up of mother/infant pairs to determine knowledge of maternal HIV infection status before birth, HIV incidence, AIDS incidence and death, and use of antiretrovirals and their efficacy in preventing HIV transmission.
- Assessing potential adverse outcomes of antiretroviral exposure among infected and uninfected children in the short and long term.
- Matching HIV/AIDS registries to birth registries to ensure complete matching of mother/infant pairs.

STATES' HIV/AIDS SURVEILLANCE CAPACITY

The capacity of states to conduct surveillance activities is limited and has deteriorated over the past several years due to inadequate funding. A recent report by the Institute of Medicine, *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*, recommends that more federal funds be provided to assist states in improving their HIV surveillance and data reporting systems in order to more accurately and effectively monitor the epidemic.² The report recognizes that states need additional funding to strengthen HIV/AIDS surveillance capacity, build infrastructure, and for electronic laboratory reporting of HIV/AIDS cases.

States' HIV and STD surveillance and epidemiology activities are instrumental to their larger public health surveillance capacities. Other recent government reports have documented the negative effect that insufficient funding has on our nation's surveillance capabilities. In September 2003 testimony to the House Subcommittee



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on Emergency Preparedness and Response, Select Committee on Homeland Security, the General Accounting Office (GAO) concluded that while there have been improvements gaps still remain in the disease surveillance capabilities of state and local public health agencies.³ Another study conducted by the GAO, *Emerging Infectious Diseases: Consensus on Needed Laboratory Capacity Could Strengthen Surveillance*, reported that many directors of state public health laboratories found staffing shortages and information-sharing abilities obstructed their ability to generate and use laboratory data for surveillance activities.⁴

The capacity of the states to conduct timely and accurate disease surveillance has become even more important in light of the September 11 terrorist attacks, concerns over bioterrorism, and new emerging infectious diseases such as SARS. State health departments bear much of the responsibility of developing systems to deal with these emerging issues, while at the same time maintaining and increasing their ability to provide traditional public health surveillance activities. In order to ensure a comprehensive response to the HIV/AIDS epidemic, as well as other public health concerns, state health departments must be fully funded to carry-out the tasks necessary for surveillance activities.

HIV/AIDS SURVEILLANCE FUNDING

While HIV/AIDS surveillance activities are essential to the tracking of the virus and in the delivery of HIV prevention, care and treatment activities, they have received virtually no increases in funding for the past decade. Approximately 5.8% of CDC's fiscal year 2003 HIV prevention budget went towards surveillance activities. NASTAD supports an increase of \$35 million over current CDC funding for HIV/AIDS surveillance activities. At a time when newly diagnosed HIV cases are on the rise,⁵ it is imperative that state health departments and

the entities that they rely on to report HIV case data, have the resources to track the emerging infections.

States core surveillance awards for FY2004 decreased due to flat-funding compounded by rescissions taken by the federal government. States have reported that these cuts will damage the effectiveness of their HIV surveillance programs by decreasing the timeliness of HIV/AIDS case reporting, allowing less analysis of surveillance data to identify temporal trends and decreasing the amount of case matching states can conduct with other state program databases such as Medicaid. Many states have also reported that they will have to reduce staff position or staff hours, computer maintenance and software updates.

¹ The current directly funded city health departments are the MSAs of: Los Angeles, CA; San Francisco, CA; Chicago, IL; New York, NY; Philadelphia, PA; and Houston, TX. The current directly funded state health departments contain the MSAs of: Phoenix, AZ; San Diego, CA; Denver, CO; New Haven, CT; Washington, DC; Miami and Ft. Lauderdale, FL; Atlanta, GA; New Orleans, LA; Boston, MA; Baltimore, MD; Detroit, MI; St. Louis, MO; Las Vegas, NV; Newark, NJ; Nassau-Suffolk, NY; San Juan, PR; Dallas, TX; Norfolk, VA; and Seattle, WA.

² Institute of Medicine, "Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act," National Academies Press, Washington, DC, 2004.

³ Janet Heinrich, "Infectious Diseases: Gaps Remain in Surveillance Capabilities of State and Local Agencies," Testimony Before the Subcommittee on Emergency Preparedness and Response, Select Committee on Homeland Security, House of Representatives, General Accounting Office, September 24, 2003, GAO-03-1176T.

⁴ General Accounting Office, "Emerging Infectious Diseases: Consensus on Needed Laboratory Capacity Could Strengthen Surveillance," Report to the Chairman, Subcommittee on Public Health, Committee on Health, Education, Labor and Pensions, U.S. Senate, General Accounting Office, February 1999, GAO/HEHS-99-26.

⁵ Centers for Disease Control and Prevention, Increases in HIV Diagnoses—29 State, 1999–2002. MMWR 2003;52:1145.



